HOUSE OF LORDS

Science and Technology Committee

Corrected oral evidence: Innovation in the NHS: personalised medicine and AI

Tuesday 17 March 2026

11 am

Watch the meeting

Members present: Lord Mair (The Chair); Lord Booth; Lord Drayson; Lord Duncan of Springbank; Baroness Nicholson of Winterbourne; Lord Patel; Lord Willis of Knaresborough; Lord Winston.

Evidence Session No. 4 Heard in Public Questions 32 - 44

Witness

I: Dr Rich Scott, CEO, Geonomics England.

USE OF THE TRANSCRIPT

1. This is a corrected transcript of evidence taken in public and webcast on www.parliamentlive.tv.

Examination of witness

Dr Rich Scott.

Q32 **The Chair:** Welcome to the second session this morning of the Science and Technology Committee. Our inquiry is on "Innovation in the NHS: personalised medicine and AI". We are very pleased to have as our witness in this session Dr Rich Scott, who is the chief executive of Genomics England.

Dr Scott, let me ask this. We heard last week from Professor Sir Mark Caulfield, whom you obviously know very well, about the work done by Genomics England in running the 100,000 Genomes Project. Could you set out for us what Genomics England's role is today, what research projects it is undertaking and how that has evolved since the 100,000 Genomes Project? Would you like to start with those questions?

Dr Rich Scott: Absolutely, and it is a pleasure to be here. As you say, Genomics England's role has evolved since its inception, when it was set up to deliver a single research project. It is now a strategic long-term delivery body operating with both the healthcare and life sciences sectors to drive the generation of evidence, innovation and the adoption of genomics at national scale.

Our role very much builds on the lessons of the 100,000 Genomes Project. Our areas of expertise, focus and delivery are in two particular areas: the building and running of national-scale digital systems to support the NHS, researchers and innovators in academia and the life sciences industry; and, secondly, supporting the development of evidence that is actionable to support the adoption of innovations that are well evidenced. That focus and, in fact, our restated mission aligns very much with the Government's 10-year health plan and the life sciences sector plan.

Our mission, as we describe it, is to build evidence and digital infrastructure to meet—this is in line with an element that is drawn out in both of those plans—the expectation that genomics could become part of mainstream healthcare and inform up to half of all healthcare encounters. That would be a real shift from where it is today. Secondly, we see that our mission is to continue to secure the UK's position as being the best place to innovate in genomics, to make new discoveries, to test innovations and, where they are proven, to deploy them so that members of the public benefit from them.

What that means in practice, in terms of our day to day now, is first to support the NHS. We provide national analytical systems and national databases to support what is a world first, which was launched by the NHS during the pandemic. It is a national whole genome sequencing service supporting the care of patients in the NHS with rare conditions,

suspected rare conditions or particular cancers. That service has now tested more than 180,000 genomes.

Secondly, again by using digital systems, we provide the National Genomic Research Library, which is a growing research resource run as a visiting library for researchers in academia and in industry to access genomic and other associated data from consented participants in our research studies. That builds on the first participants in our research studies, the 100,000 Genomes Project, other research studies that we run and, crucially, people who have testing in the NHS and who actively consent to joining that research library. It is a growing resource to support that research.

A crucial element of our role in those two distinct areas is in being able to link clinical care and research. That is partly through that active consent process that I mentioned; it is also through the digital systems and the governance that we have developed with the NHS and with people across the life sciences sector. I will give you one specific example of how that works.

By way of background, I am a clinical doctor and a specialist, a consultant in rare disease, at Great Ormond Street. One of the areas you have heard of where we use genomics and whole genome sequencing at the moment is in diagnosis of rare conditions. When we see a family and test them, we find many more answers than we did 10, 15 or 20 years ago, but we still find an answer in only a portion—in fact, the minority, if you look at all families. Because families consent to join that research library where they want to, researchers can keep looking for answers. We call that diagnostic discovery; where they find one relevant to a family, it can be passed back to the NHS teams to inform their care. The benefit is for the individuals in the health system, as well as learning at large.

As well as running those systems, we run specific research studies where we see the need for proactive development of evidence to inform future adoption. One of the biggest areas and focuses for us at the moment is in the potential for whole genome sequencing to support better and earlier detection of treatable, severe, rare conditions in newborns, alongside the existing heel-prick screening. To develop that evidence, we are currently running the Generation Study, which is a research study delivered—as we always do with these big research studies—in partnership with the NHS, so that the evidence we generate is very much based on the real world of delivery in the NHS to support that adoption. That programme has now sequenced just over 50,000 families. It will recruit 100,000 by the time it has finished.

We are just beginning the design phase of a second programme announced last year as part of the 10-year health plan and the life sciences sector plan to develop evidence and digital systems—that is the theme that runs throughout our work—to support the more accelerated and evidenced adoption of the use of genomics in the adult population setting. Specifically, for example, an area that is referred to as

pharmacogenomics is looking at DNA sequence to identify people who might be at higher risk of adverse reactions to a drug or who might benefit in terms of the effectiveness of the drug from a substantially different dose. That is a really big area, as well as looking at the prediction of common disease. That is not the limit of where we work, in terms of evidence. I am sure we will talk later about how we partner with others to make sure that the evidence they are generating in their natural course drives that adoption because there is a lot of importance there.

Perhaps I may say a word on how we regard evidence, how we shape ourselves and how we have learned over the years. Evidence is, of course, about the scientific end of the spectrum. So I have a new test or algorithm: how well does it work to detect what I think it needs to, how equitably does it work or how safely does it operate? It is also about cost effectiveness and public opinion—their views on how they want their data used. For us, ethics, equity and public engagement are a core part of our work and of the evidence that one generates so that, if genomics is adopted, it is done at scale and in line with public expectations. I hope that has given you a sense of where we have moved from that initial journey in the 100,000 Genomes Project to our focus now and a little about how we focus on the mindset that we take to all of the areas.

Q33 **The Chair:** Thank you very much. We have a lot more questions for you. I would like to ask one. About 500 people work for Genomics England. What is the rough division between academics and clinicians of that 500?

Dr Rich Scott: Our workforce is quite diverse in terms of their skills and it reflects those areas of focus that I mentioned. The single largest component of our workforce is people with a technology, software-engineering and data-science background, often with an academic element but not always. That mirrors the building and running of those national-scale systems, which is an important and complex area. We also have clinicians like me. We have people expert in delivery of programmes—for example, the Generation Study—and running programmes on the ground. Then we have expertise around those areas of ethics, equity and engagement, which are important, but the largest single portion is around digital technology and data science.

The Chair: So you have a relatively small number of clinicians. Is that right?

Dr Rich Scott: Yes.

Q34 **Lord Booth:** Thank you, Dr Scott, for coming in and giving evidence to us this morning. I would like to explore the future of Genomics England a little more. Part of the reason that we are doing this inquiry is out of excitement for the future of personalised medicines and genomic analysis in the age of AI. I also feel it personally, because my husband is embarking on a treatment of CAR-T. He has started by having his cells harvested and he will be taking the treatment in about three to four weeks' time, so it is very personal to me.

When Sir Mark Caulfield gave evidence, among the gaps that he identified was a systems biology approach that integrates RNA proteins and other types of data, as well as the need for more diverse data. Can you set out for us, please, the research and projects that Genomics England will prioritise in the future and, more specifically, what excites you?

Dr Rich Scott: Absolutely. We see our role and the way in which we express our mission as to deliver those digital systems and support the development of evidence that drives adoption. That is what we very much have our eye on—the line that is there in the 10-year health plan and the life sciences sector plan about genomics. That is often meant in a broad sense. In terms of terminology, people often think about genomics more strictly speaking, as the study of DNA together with other similar areas of biology—so RNA, the molecule that is produced from DNA, through to proteins and sometimes into the metabolites. People talk about omics, and what they often mean are those different areas of DNA—RNA protein and metabolites. In that area, that line in the 10-year health plan about the potential for genomics to play a role in up to half of healthcare encounters is one for which we see the potential. It deeply excites me personally and us as an organisation.

The first thing to say is that it is important to recognise that there is an awful lot more distance to go in terms of the potential for DNA alone. It does not diminish from the wider potential but that is why we continue to focus there—for example, that newborn genomes programme, the adult population programme and pharmacogenomics. However, this is also about bringing together a more systematic approach, which is something that we have already been doing in the past few years, both in rare disease and cancer. I will give you a couple of examples and explain how we see that in the future.

In terms of cancer, one of the big areas of focus for us over the past few years in a programme that we called Cancer 2.0, was bringing in image data. That meant the histopathology slides, which are the slides that teams look at down the microscope to identify what the cells in a cancer look like. We digitised them in a standard way and made them accessible alongside the DNA and clinical data on our participants. We did that with images from radiology and so on to help judge, for example, the growth and change in size of tumours. That has been an exciting area that we expect to continue to grow, where we partnered with various people in academia and industry because it is a growth area, in terms of not just the biology but beginning to tap into this potential, particularly from AI, whereby some of the hardware and tools are changing so fast. We are proactively partnering with some of those organisations.

For example, we have got an active partnership with an organisation called InstaDeep UK, which is London based and owned by BioNTech. It focuses on those areas that I have highlighted in our data, harnessing AI with multiple different types of data. People often talk about multimodal data, multiple types of data. In rare conditions, our focus has been particularly on the other omics, those other types of molecular data. So

that is generating RNA and proteomic data, and we are now looking to focus on metabolomic metabolic data. We see real potential there.

In that area, we see our role as working with the people with the best ideas to harness them. We have worked with Google DeepMind on some of its algorithms to help explore how well they are working in using some of these data, and with people who are generating their technologies to help, again, with that evidence piece about how useful they actually are in clinical care or to drive discovery. That deepening of the data we see as really important, as well as understanding and supporting people in learning how to bring it together, which is new and really important.

The diversity point sits alongside it. Historically, we know that certain communities are underrepresented in healthcare research in general, including genomics research and databases. There has been a big focus for us for the past few years in a programme we have called our Diverse Data programme, which is specific to ensure that the National Genomic Research Library increases its representation of historically underrepresented communities. We are also committed to embedding that in everything we do. So, in the Generation Study, the adult programme and others, we are ensuring that participation is diverse and representative.

There is a key point about the system that we have developed with the NHS and others—the learning system, as we often refer to it, where clinical care and research work hand in hand. A good example here is on questions around diversity. As we know, we will keep learning for years—in fact, decades—and we must. This is not just about saying, "Over the next two, three or five years we must make headway". It is also about creating a system that continues to learn so that that representation can continue to grow.

Lord Duncan of Springbank: I have a very quick point. How does Genomics England interrelate with the other parts of the UK, which are Scotland, Northern Ireland and Wales? What is the relationship there?

Dr Rich Scott: Our funding from the Government comes from DHSC R&D capital funding, which is devolved. For example, for the Generation Study that funding is focused on England, and that is where the recruitment happens. Currently, our work in supporting the NHS is focused on England. Historically, we have worked with all the devolved nations—for example, on the 100,000 Genomes Project, where additional funding was provided to support recruitment. We work really closely with, for example, the chief scientists in the devolved nations. It is an area of continued future focus, and we see a real benefit in UK-wide thinking.

Lord Duncan of Springbank: Is there a comparable research funding opportunity that gives you the prospect that you will be able to collaborate in future?

Dr Rich Scott: There is interest, but it is an area where at the moment our funding from that DHSC R&D capital is devolved.

Q35 **Lord Willis of Knaresborough:** Dr Scott, I am excited by your excitement. You clearly feel strongly about the whole issue of Genomics England and its development. For many of us, Genomics England is a fundamental element of the Government's 10-year plan, and unless it is allowed to develop and take its spot then we will miss out on a lot of other things. What has surprised me about your comments so far is that, when you are talking about the expansion of Genomics England around the whole UK, you have not mentioned that AI is fundamental to its achievement and that, without it, you would not be able to do that. You must recognise that getting researchers from the health service is very difficult, to put it mildly. Having spoken to some young doctors who have just qualified, literally last weekend, I found that none of them was going into research because they could not afford to do that. That is a real issue. To what extent do you think AI is going to enable a real change to make the theoretical possible? What does the UK need to do to prepare for that? What is Genomics England doing to be ready for it? What does it need to do differently from what it is doing at the moment?

Dr Rich Scott: I wholeheartedly agree that AI is going to be at the centre of this. There is a really interesting piece that you touch on there, particularly with the junior doctors. I think back to myself at a similar stage, and there is a theme here more generally about broadening the impact of genomics and related fields. Some of that comes down to enablers, and I will come on to specific thoughts on AI.

There is also a general theme on whether that is about education or embedding genomics. If you ask someone at medical school or university who is not covering that field, they will say they feel underskilled, and that is probably true of a lot of doctors and clinicians more broadly. Part of what we and the NHS need to do in the coming years is to ensure that that embedding is done in a way that makes it accessible to the public but also to clinical teams. Not all of that actually needs them to be expert. Think about the understanding that, for example, a GP might have if they are using a cardiovascular risk-estimating thing that pops up in their GP system; it is fine for them not to understand it. What they need to know is enough to use it, trust it and understand its safety, and to be able to explain to the patient in front of them how their data is being used and so forth. Digital integration is a big part of this for genomics, as well as education in a way that helps people to understand what they need to do but recognises that everyone does not need to be an expert in everything.

I wholeheartedly agree that AI is going to be a critical enabler here, a multiplier. I had the same excitement about the potential for genomics five years ago before I, or perhaps most of us, understood how soon that wave of AI innovation was coming. I see it as additive, and it is imperative that we set ourselves up well to support it. It is an area where I see Genomics England as being well placed to play a strong enabling role. Some of that comes from our ability to get hands-on partnering with even quite large research organisations that you might imagine would be the best placed. Even there, we are at the stage where understanding

how to leverage the technology best is important. There are also pieces around continued investment in digital infrastructure—ours, but also that of others—thinking about the capacity in the UK in AI and compute, and making sure those that investments continue.

There is another important piece in AI, just as there are in other areas around regulation and standards. Those words sound like they are decelerators of innovation but we see a real opportunity for the UK to be on the front foot here. We have expertise nationally to say, "This is how you can demonstrate the safety, quality and equity that means that, if an algorithm is supporting it, you will be a real destination, as we see more broadly for genomics, as the place to work and demonstrate the power of whatever that innovation is". That is really important.

I agree that it is also about the education and support of those specific researchers. That often goes hand in hand with the detail of the technology as it changes. That is an area that we work really hard and are focused on at the International Genomic Research Library to ensure that, as specific tools develop and become available, there is training for them. A few weeks ago we hosted a young researchers' event at Genomics England, and we have young researcher representatives as part of our research network, and we have had strong buy-in and excitement in that area. Then there is the broader skills piece that overlaps with that, and that is vital too.

Q36 **Lord Patel:** My question is in two parts and is rather long so you could take up the whole morning in answering it, but hopefully it can be done briefly. The first part is related to the NHS 10-year plan, which has the fantastic ambition of harnessing advances in AI and genomics, as you partly touched on. It states that it will be an advantage that the NHS is best placed to have this in place, and it will propel the NHS into a position of global leadership. Do you think that is overstating it?

Dr Rich Scott: I do not think it is overstating it. In genomics specifically, the NHS is held up already as being a global leader, if you think about comparable health systems.

Lord Patel: Do you think a patient in Barnsley is getting the same genomic testing as one at UCL?

Dr Rich Scott: I am sure there is diversity of provision but that does not mean that the job is by any means done. When it comes to the UK showing leadership internationally, there is almost unanimous recognition of the NHS's world-first national implementation across all parts of England, ensuring that the clinical pathways flow not just from single centres of excellence. From the beginning, that has really been in the mindset of the 100,000 Genomes Project. It is the same way that we work, for example, in the Generation Study: thinking that this is about delivering research, and then, when it is proven and rolled out, deployment across the system nationally and in ways that reach all parts. That is really important. It makes research different and sometimes more complex and slower, but it is also the thing which really focuses on that

universal benefit, which is at the heart of what the NHS is about and what fully harnessing the potential is about.

Lord Patel: Do you think the NHS 10-year plan has an implementation plan?

Dr Rich Scott: From the perspective of genomics, it has been very thoughtfully put together. In terms of, for example, the areas where we are focusing in the coming years, it looks at that sort of headline—that potential for genomics to really expand—and says, "What are the evidence gaps? What is the digital infrastructure that is required?"

Lord Patel: So there appears to be a clear plan about how genomics can be implemented in management of patients. But the NHS 10-year plan also has a great ambition to use genomics as a prevention plan. Do you think that is well thought-out, and how will that be implemented when we talk about prevention in the general population?

Dr Rich Scott: Perhaps the area where I am most excited in the coming years is that move. I am a genomics doctor focused on rare disease diagnosis, as you highlight, Lord Patel. That is where genomics has made a big impact over the last few years alongside cancer. It is fantastic what has been done, and that is just scratching the surface. In terms of the potential of genomics, I believe that thinking more broadly about the 10-year plan, setting out that ambition to shift upstream and increasingly into prevention, is where we see the potential for genomics to play a big role. As you highlight, it is also an area where we are right at the beginning of the journey. That is where our focus is, one example being the Generation Study—the Newborn Genomes Programme—which is about being more pre-emptive about a wider range of early onset conditions.

Lord Patel: Because I was coming on to that question, obviously your 100,000 Genomes Project was usually successful, but it was focused on rare diseases and some cancers, while the Generation Study of 100,000 newborn genomes has no clear entity to it—or does it?

Dr Rich Scott: It is very specifically about providing evidence on the potential for whole-genome sequencing to identify and intervene earlier for children where there is a severe, early-onset, rare condition similar to those that are currently looked at on the newborn blood spot. At the moment nine—shortly to be 10—conditions are looked for. The Generation Study's primary goal is to generate evidence around whether whole-genome sequencing could be the first step in expanding that, and in the study we are looking for just over 200 conditions similar to those that are currently looked for. I will give you just one example that was shared by the family and in the press: a little boy whom we identified in the newborn period and fed back in the first few weeks of life to have a misprint in a gene called retinoblastoma—

Lord Patel: I think Professor Caulfield mentioned that in his evidence.

Dr Rich Scott: That was to identify that he was at increased risk of these rare eye tumours. In fact, because of that intervention he could have detailed examination under anaesthetic to allow the multiple tumours to be identified early and treated in a way that the team believes will have a positive impact on his long-term—

Lord Patel: So the Generation Study will also focus on rare diseases but it will identify the risk in the newborn.

Dr Rich Scott: Correct.

Lord Patel: So, again, it is a specific study. The National Cancer Plan also has an ambition that, for everybody who needs a genomic test for cancer as they develop biomarkers, it will be available throughout the NHS. That will be the same problem: is it going to be implemented in Barnsley in the same way as at UCL, and how will that possibly work?

Dr Rich Scott: That is another area where it is very much about NHS delivery, where we are a delivery partner providing digital systems and analytics, particularly for the whole-genome sequencing element, which is only a subset of cancers at the moment. But we are very much there alongside NHS England and supporting its plans.

One of the areas that I would highlight and which we support the evidencing of is a unique international asset: the NHS Genomic Test Directory, which NHS England refreshes each year. I think part of the mindset there—again, allied with the broader mindset—is making sure that that that is about national commissioning, and that national mindset is a really important area of giving optimism for successful delivery against those areas of plan.

Lord Patel: I was going to ask you briefly about barriers. One of the barriers in the NHS in particular is how the structures are organised. One reason why Barnsley patients might not get the test while those at UCL can is because the commissioning system does not allow the implementation of these things; the ICBs work differently in different regions. Do you think the current structures could deliver all this uniformly in the NHS in England?

Dr Rich Scott: One area to note—I point out that Genomics England is a delivery partner for the NHS rather than wanting to comment specifically in detail about the set-up—is that genomics is commissioned nationally in the NHS in England, which comes with clear advantages in that co-ordination. That links to the point on the test directory.

Q37 **Baroness Nicholson of Winterbourne:** Thank you so much for everything you are telling us—it is fascinating. I have known three families of people who happen to have worked with me over the years and who have been a part of these studies because they had specific diseases, so I know how much it means to them. I was wondering, since access for all never happens—it is really not a human condition—might you perhaps put a little bit more effort into national knowledge? As you

have AI, it is so easy to make it accessible in information and knowledge for all so that, as there is not access in Barnsley but there is in Birmingham or somewhere, people get to understand all the barriers that are facing people and how much everyone is working to try to overcome them. Otherwise, there will be huge disappointment. There is never any access for all.

Dr Rich Scott: That is a very good point. One of the areas, partly building on an area Lord Patel was asking on, is how we will see that shift from genomics being an important area for certain people to something which lives up more to that potential of being much more broadly beneficial where it is evidenced. Our adult population genomics programme is seeking to develop evidence in those areas; I mentioned that area of DNA informing medical prescription for so-called pharmacogenomics, but there is also broader use.

One of those themes—again, it is identified in the 10-year health plan—is from hospital to community, and a real theme for us in that it is exactly what you identify, which is making it something which people themselves are empowered by and understand. That is a really big area for us in terms of understanding what people's expectations are and what they need to know. That is partly because it is important that we shape our research studies, but it also relates to where things are adopted and how clinical care is adopted.

It is also a really important part of empowering and reducing barriers. Our public engagement work has really focused on that. In the last few weekends, in this early design phase of our adult population programme, our teams have been spending time across the country, most recently in Newcastle, with members of the public who have not been selected because they know about genomics or DNA but because they come to this quite fresh, to understand how people want to engage. We wholeheartedly agree that that is a really important part of promoting its adoption and the benefits being felt equally.

Q38 **Lord Duncan of Springbank:** I want to touch on resourcing and understanding the funding that you have. Just as a background, the last time you produced a report was 2022. Is that right?

Dr Rich Scott: That was the last time we produced a more lay-accessible annual report, but, in the standard way of any company, we do produce annual reports.

Lord Duncan of Springbank: I am trying to understand what resources you have to play with. Obviously, there is the life sciences industrial strategy and a significant sum of money, about £650 million, is set aside for genomic medicine. How much of that allocation did you get?

Dr Rich Scott: That figure is specifically money to support Genomics England's work. It is our DHSC R&D capital settlement for the spending review period that was covered by the announcement.

Lord Duncan of Springbank: That is helpful. So, in trying to

understand the resources you have got, are you resource limited, in that you are able to budget within your approach with the money you have, and then you hit the buffers, you hit the edge, and you can do no more? Or are you able to say that there are areas where there is specific excitement or potential and then you revert to government to say that this area would benefit from further funding, in addition to that already allocated?

Dr Rich Scott: We were really delighted with two things, as I am sure you can tell from my answers: the content of the 10-year health plan and the life sciences sector plan, and the direction of travel. Also, we worked really closely with government on the shape of our settlement. In terms of the funding that was allocated and the programmes we set out, we think that works really well, because we have thought very carefully about where we see our role in the coming years.

A really important part of how we are established as a government company is that it gives that important flexibility at a certain level, making sure that we can respond to areas of potential innovation rapidly. We are comfortable with both the settlement and the way in which we interact with government

Lord Duncan of Springbank: A more difficult question, I suppose, is given that, ultimately, the Government are your sponsor and master in this regard, are there areas where you could see improvements in the engagement, where you would wish to see changes in the way that things are happening, or are you content with the current model?

Dr Rich Scott: We are content with the current model.

Lord Duncan of Springbank: Finally, as this exciting area expands, and it is likely to expand, the need for resources is likely to expand in lockstep with that. What is the process whereby you engage with government to do that? Is it an annual discussion, where you set out your ambition and they examine it? Or is it constrained by the 10-year plan itself and therefore nothing can happen for 10 years? What is the process on an annual basis whereby you engage with government to say, "Things aren't what they were last year. Opportunities have now presented. Here is how we want this to be reformed"?

Dr Rich Scott: We engage during the year. We work closely with the DHSC on the fine detail. Then, broadly, we work, as lots of parts of government do, linked to the spending review cycles. Those are the natural major checkpoints beyond the fine-tuning.

More broadly, thinking about some of the areas of opportunity, it is not all about funding resource. This is an area where the 10-year health plan, the life sciences sector plan and a lot of the other parts of the broad government, public sector and life sciences ecosystem work together on focusing resource on opportunity cost and thinking about that.

One of the other real areas of optimism for me, which is something that we have learned about as an organisation in the last 10 or 11 years, is how a lot of our impact comes from how you work together with others in the ecosystem. It is that co-ordination piece which I think the Government have really focused on in the 10-year health plan and the life sciences sector plan. You see cases, for example, like the partnership on cancer vaccines with BioNTech where the whole of government engages with, in this case, an industry partner that has got a real opportunity. It goes all the way from clinical delivery with NHS England and ourselves—co-signatories on the partnership with BioNTech—with MHRA thinking about the regulation and so forth. It is that joined-up bit that is really empowering.

Lord Duncan of Springbank: I have a very final point on human resources within that. Obviously, your capex and your funding for actual research is, as you describe it, in a good place. Are you content with the way in which funding is happening for students, studentships and ongoing research in universities? Are you able to influence how that is funded and directed through dialogue? Or is that something which you are less engaged with?

Dr Rich Scott: We have not played such an active role. We do when thinking about training that is specific to genomics. It has not been an area where we are highly expert, but it is a really interesting area to explore.

Lord Winston: It is good to meet you, Dr Scott. You may have just heard the end of the last session.

Dr Rich Scott: A little bit.

Q39 **Lord Winston:** There was actually quite a relevant point mentioned by Dr Markowetz, which was that the contact between clinicians and scientists was not, in many ways, as it should be. You clearly have a lot of experience, given the sort of work you have been doing, to talk about that.

One of the things he raised was what we would call, in effect, clinical academic fellowships. The Academy of Medical Sciences shows very clearly that there has been a massive drop in the funding for those positions. At your institution, Great Ormond Street, and the Royal Postgraduate Medical School, when I was there, those were the bench to bedside things that were very relevant in paediatrics and very relevant in my field of developmental biology and fertility. Heart disease certainly has been massively changed by that, and we have seen it in all sorts of other medical areas. There is clearly a gap, and he mentioned that. I wonder whether you would like to mention that from your point as a clinician.

Lord Willis talked about the lack of money that some students perceive. Actually, the NHS is quite ready to pay half the salary very often. It is quite easy to do that. But the funding of the other half almost invariably

comes from charitable funding: it certainly does at Hammersmith and Imperial College. I wonder whether you would like to comment on that, because I think it is a relevant point.

Dr Rich Scott: Yes. First, I would not describe myself as an expert in those funding structures. I was more distant from it, personally and at Genomics England, working with those people but not so actively involved in thinking about those funding structures.

One of the areas of biggest focus for us, as you can tell, is thinking about how we make sure practically, including those individuals at those stages of their careers, and I mentioned that there was strong buy-in from early-career researchers and engagement with our programme, that the system is set up so that there is a really clear path to do great science and make a great difference in clinical care.

Many clinical academics will have a particular eye on the direct, translational, clinical, in front of your eyes impact that can be had. That is one of the things that is most rewarding about bringing those two worlds together. Healthcare has to be under a certain governance, and it is very clear that there is also separate governance, which Lord Winston is very expert in. But the way in which we work with the NHS and with researchers to make sure that those two worlds can work together in the right, carefully governed way, creates a pathway for making a big difference to families and to people being able to set out really clearly to funders the impact that their care will have. We have a particular focus on that translational element.

I will give one example of a discovery that was made in the last couple of years in the National Genomic Research Library. I mentioned earlier that a lot of children with rare conditions still do not have a diagnosis, despite the "best in world" testing that is available through whole-genome sequencing. A couple of years ago, two research teams, both in the UK and both working at the National Genomic Research Library, made a discovery of a new genetic condition, which is probably one of the most common that had been made for years. It is called ReNU syndrome, rather poignantly named after the renewed hope that families had once they had received the diagnosis. That was made by British research teams, who could identify the cause and, because of the focus of our teams and the governance that we have set up with the NHS, recontact the families within days so they could benefit. It could also drive the science, because they could provide feedback on the symptoms that their children had and so forth, and that joining up of the of the systems, making sure that that research can happen fast, is the sort of research that I think makes really strong cases for funding. That is really important.

Lord Winston: There is a problem with genetics. I declare a minor interest: I am a patient at Moorfields Hospital. I have Fuchs syndrome, which changes one's vision. I was going quite seriously blind at the time of Covid and it did not really get much treatment. The way that treatment

is done now is not really to understand the genetics but to find alternative ways of relieving some of the symptoms, and in my case it has been pretty successful. However, the basic problem with so many of these gene mutations is that we need to have a better idea of what is really going on, and that seems to be much less available.

Dr Rich Scott: I agree that it is harder, but it is a real area of focus for the research. For example, bringing those other omics, other molecular data types and things such as imaging together with the DNA data is really powerful.

An important theme that I have not touched on yet is the wave of potential in the coming years, which has come faster than I think people expected, in the area of genomics-informed therapies. One example I mentioned was cancer vaccines, which look at a tumour in detail and create a genomics-informed, personalised vaccine for it. In rare conditions, there is a similar area of growth, as I am sure Lord Winston personally knows, but that can sound less accessible than what this wave of possibility brings. Using, in some cases, some of the same technology developed for mRNA Covid vaccines, you can develop much more targeted therapies looking at the specific genetic cause of someone's condition. That is an area where we see an enormous potential for helping us to discover the cause and understand some of the biology, but also identifying people who might have the potential to benefit from this.

That is another really nice example of where the system in the UK as a whole can work well together. The MHRA is playing an active and thoughtful role in thinking about the right regulation to place around an area that is really novel. This is an area where, again, people internationally look to the UK, because of the potential of our infrastructure and the positive signal that the MHRA has sent about wanting to engage thoughtfully on this. That is really important as well. It is still complex and the evidence needs to be generated, but there is real potential for greater patient impact and for the UK genuinely to be a place to come and run studies and, where these work, to roll them out and benefit from them.

Lord Winston: You have already been asked today about access to treatments. Something that strikes me as a clinician is that a huge number of patients who are not perhaps in specialist centres or in major areas find it very difficult to get any explanation at all of the genetics. They know that something is wrong—they hear that there may be a mutation and there may be some risk of having an abnormal child as a result—but it is difficult for them to get treatment or to get it funded within the NHS, even though it would be cost-effective, because of course the funding is usually very short-term. Do you think that is a problem?

Dr Rich Scott: It is definitely a complex area for any health system. It comes back to some of the points on education and understanding where genomics for rare conditions might be beneficial. It is also an area where the NHS has shown how strong the national offer is and how the

universal mindset can support things. Rare conditions or unusual clinical situations make it complex to make sure that everyone is catered for. A well-known term that people now use, the "diagnostic odyssey", refers to the fact that people with rare conditions take an average of five years—this is an international figure—to get a diagnosis. That is an area where the NHS, as set out in the 10-year health plan, has already made some positive inroads. The Generation Study, for example, is exploring one area where for certain conditions we think we could do better, and we are developing evidence. The NHS, through the 10-year health plan, is being clear that it is a continued area of focus to shorten the diagnostic odyssey.

Lord Winston: When we were developing pre-implantation diagnosis, we saw clearly that in many places clinical geneticists were rare, and that patients' chances of getting a detailed discussion of how bad the situation was, or how possible it would be to get treatment, was absent. Do you think that is still a problem?

Dr Rich Scott: I am a clinical geneticist by background, and I think it is still a relatively small workforce. There are two points here. First, the workforce has grown in recent years, and a really thoughtful approach is being taken by NHS England to the broader genomics workforce—genetic and genomic counsellors—and in thinking about how to integrate that into clinical pathways more broadly. What is important is that people get the right information from experts. As a clinical geneticist, I am often not the most expert person at Great Ormond Street to deal with a particular condition; that is often the treating positions of that care pathway. I know that this is a continued area of focus for the NHS, and it is one where the NHS has been really thoughtful.

Q40 **Baroness Nicholson of Winterbourne:** I have a small follow-up on communication. A large number of people in Britain do not speak English and therefore the use of language with AI, which is so simple and easy, seems to me to be a fundamental priority. I give an example: we know that, particularly in some areas of London and some other areas of Britain, the take-up on immunisation of crucial things for children is minimal, and as a result the outcomes are appalling. You have a part to play there, I would have thought, and not just to the mothers—although it is mainly mothers who will not speak English—but to the children themselves. Some of the immunisations do not need to be done until they are 12 or 13, and the children could trigger them themselves if you felt that way.

Dr Rich Scott: That is a really important point. For example, in the Generation Study we are spending a lot of time focusing on that and learning. This comes back to our broad take on the breadth of evidence that is required here. It is about the science, and the cost-effectiveness is vital, but you do not stop there. It is about understanding how this plays out on the ground and is accessed by the communities who need it, sometimes by running research programmes embedded in the NHS. The Generation Study is recruiting at 72 sites across the NHS, and we have

deliberately chosen a diversity of sites, with diversity on various axes. For example, we are making sure that we are heavily represented in urban areas but also rural ones, and that there is diversity in the populations they serve.

Often, the lessons are ones that you do not necessarily expect. We are doing a lot of work around language and accessibility, but it is also about where people hear about the potential and so forth. That is why, in our adults programme, and I mentioned the engagement work we are doing, before we even design the programme, we have a real focus on engaging with multiple different communities to understand what evidence gaps we need to fill in those sorts of areas.

Q41 **The Chair:** Dr Scott, you have been wonderful. Do we have more questions? Not too many more, I hope, for your sake. However, before we move on to further ones, I want to ask you this: you have already been asked about barriers to widespread access to genomic medicine. What is the role of a commissioning model? Is there a commissioning model that does not allow for enough genomic tests to be run? Is that an issue, in your view?

Dr Rich Scott: In terms of the NHS in England, with the commissioners for genomics, as with all commissioning, it is always a balance around resource allocation and prioritisation. In any area, that is an important consideration. Also, it is about opportunity cost and, with this great breadth of possibility, thinking about how one makes choices on where one either generates evidence or learns about deployment first. That is important.

This is also an area where having a National Health Service puts the country well in advance of many others. We see that, together with the sustained investment from government, the private sector and the NHS in its commissioning decisions, as being something where you can take that thoughtful approach and be really proactive about those choices.

The Chair: So you do not think that the commissioning model at present is a barrier?

Dr Rich Scott: No. The genomics commissioning model has been considered thoughtfully. The national approach is really useful.

Q42 **Lord Drayson:** My questions will focus on the commercialisation aspects of the work that Genomics England does, accepting and recognising the terrific impact it has had on health research since it was founded back in 2012. I remember, because I was active in the industry at the time, that, when GEL was set up, it had as part of its remit kick-starting a genomics industry in the UK. That seems to have been dropped. It is not mentioned in your recent report. Is that the case?

Dr Rich Scott: On our mission, which I mentioned earlier, I will draw out that element. Supporting genomics innovation and the genomics industry is very much part of our mission. Our mission statement as an organisation is to build digital systems and evidence in order to support

the adoption, by 2035, of genomics in up to half of all healthcare encounters and—this is the pertinent element—to secure the UK's position as the best place to discover, prove, roll out and benefit from genomic innovations. That is very much in both academia and industry. There is a number of examples over the past few years, in terms of how that has played out, perhaps in ways nobody could have anticipated.

Lord Drayson: Perhaps we can get into that, but that is a pretty long sentence to describe a clear original objective: to create a UK industry that contributes growth to the UK. You will be aware that this committee has carried out an inquiry into why the UK has failed to translate our excellent scientific research base into wealth and growth for the country.

So, going into this a bit further, the Treasury has, through the NHS, provided £1.3 billion in funding for GEL. As we heard last week in the evidence from some of your colleagues, nothing has really gone back to the Treasury in terms of growth impact. It is remarkable how the companies that have benefited from GEL are Amazon, in terms of cloud storage, Illumina, in terms of sequencing, and the various Google companies, in terms of analysis. The one company we could identify as being, you could argue, a product of the work done at Sanger was Congenica, which was acquired last year by a French company. What has gone wrong?

Dr Rich Scott: On DHSC investment in Genomics England, the figure up to now is just under £900 million.

Lord Drayson: But we heard last week that the total commitment adds up to £1.3 billion. Is that not correct?

Dr Rich Scott: That is the current investment, and future investment has been committed.

Lord Drayson: It is running at approximately £100 million to £120 million a year. Is that right?

Dr Rich Scott: It will vary each year, but that is correct for some of the years. Your point is partly about the breadth of impact. We have worked with Congenica from early in the 100,000 Genomes Project. We continue to work closely with it today. We work with industry in a number of ways. That is with international partners and—

Lord Drayson: I have a few specific questions. Perhaps we could be efficient in this. The Illumina contract was not completed. Is that correct?

Dr Rich Scott: The original Illumina contract was not completed; it will run to completion in the next year or so.

Lord Drayson: Was the Amazon contract completed?

Dr Rich Scott: Yes.

Lord Drayson: Do you disclose the terms of your agreements? By this, I

mean your data access agreements and the commercial partnerships that you have with companies such as Google, GRAIL, BioNTech and others.

Dr Rich Scott: We do. Let me explain the way in which we partner with different companies, both large, multinational, UK-based companies and smaller ones. We put a lot of focus on UK SMEs. We have 30 active commercial partnerships accessing data in the research library. That includes a substantial number of small and medium enterprises, including UK-based ones. We also partner with, for example, Oxford Nanopore, which is a large company providing an innovative sequencing technology; we have worked actively with it over the past few years to develop evidence to inform NHS adoption.

Lord Drayson: Dr Scott, I have studied your financial statements at Companies House. I was struck by how little detail there is in terms of the revenues that Genomics England has generated over the past few years. The fact that you have not published a full annual report since the period covering 2022 seems strange to me. Can you explain why you do not put this information in the public domain?

Dr Rich Scott: The Companies House publications include the substantial detail and beyond, including the 2022 report; that was about explaining our work and making it more accessible to the public, rather than it being different in terms of a level of detail.

Lord Drayson: You will recall that it was unusual to set up GEL as a government company; it is 100%-owned by the Department of Health. All of the funding comes from taxpayers' funds in the department, and it is hard to determine where the revenue generated by GEL is coming from. It is good to hear that you have these agreements. If you could write to the committee setting out the list of these companies and what they are accessing, that would be really helpful.

I am finding it hard to understand why GEL has not been able to generate significant revenues in facilitating the creation of a UK genomics industry. I think you were here to listen to Professor Markowetz's evidence, as an example of a young UK biotech genomics company that found it, as he described it, impossible to enter into a commercial agreement with you. He described it as GEL just not being set up. It is excellent at putting academic agreements in place, but it has not, as he put it, worked out how to do commercial agreements, despite being in existence for more than 10 years. Why is that?

Dr Rich Scott: I joined just after that, I am afraid. I did not hear that comment from Professor Markowetz and am not aware of that issue specifically. We have a really strong partnership with more than 13 UK small and medium enterprises. It is a growing area of focus for us. We make sure that, for example, SMEs have a clear and simple path to accessing the data. I will also make a general point about the way in which we consider the focus. Our focus, as an organisation owned by the

DHSC, is on benefit to UK plc, not solely revenue for Genomics England per se, and I think that is healthy.

One example is the BioNTech deal, where BioNTech partnered with the UK Government last year and announced a £1 billion investment in the UK, including through areas of partnership, and we are supportive of that. It is that UK plc rather than Genomics England-specific view that is really healthy and important. We generate revenue to ensure fair return on access to data, but we also ensure that the focus is on UK plc benefit overall.

Lord Drayson: Dr Scott, I am pushing you to try to understand—you have been CEO for a while, and before that you were deputy chief executive—why, on the commercialisation side, the actual generation of wealth for the United Kingdom has not happened, particularly as you have so many directors on your board who have deep commercial experience, particularly in US tech. Why are there so many members of your board who have that background, including from Amazon, and two from Google?

Dr Rich Scott: I do not think we have any directors on the board with a link to Amazon. We have a director who is a CTO of Isomorphic Labs who has recently joined.

I will just step back and make a point on the genomics industry and ecosystem in the UK in general, because this is what we are focused on. We are not focused solely on a Genomics England revenue-only view. The genomics market's capitalisation is about £5 billion, and it is growing 12% year on year. We do have a world-leading genomics industry in the UK, and that is very much what we are focused on. Genomics England focuses very much on these sorts of partnerships. They are definitely areas where we continue to learn. I do not believe this is an area where we have not made substantial impact and progress.

The understanding of the model has evolved in the years that we have been in existence, but the creation of that end-to-end view, where you ask as a company whether you have the path to something landing in clinic, is an area where there is real success and ongoing momentum.

Lord Drayson: It is important, Dr Scott, when you describe the British genomics industry not to conflate companies that have some of their operations based here, such as Illumina, and companies that are owned outside the UK, where the value generated flows outside of the UK. This committee is specifically addressing the issue that the UK has, which is that it is not generating the wealth in-country to sustain its public services and, as a result, as you will have probably heard, there are cuts being made in research budgets, because the country is struggling to afford all of this.

Genomics England has been very well funded through NHS funding, and I see you have a number of US venture capitalists on your board. I put this challenge to you. We heard the evidence from your colleagues last week;

I think the phrase used was that the Genomics England board had "smelled the coffee" on this issue. Would you characterise that as being accurate? Has the Genomics England board "smelled the coffee" on the problem it has relating to this failure to translate this excellent science into wealth here onshore in the UK? I remind you that Isomorphic is a subsidiary of Alphabet, which is not a British company.

Dr Rich Scott: The Geonomics England board is very focused on it and very reflective of how the ecosystem has changed. I genuinely believe that the areas of potential are much stronger now than they were. They have changed. The board is absolutely very engaged on this. It is an area of continued focus. We reset our mission last year to align with the 10-year health plan, very much seeing our role as ensuring that industry is actively engaged and recognising that we are part of that—we are not the whole of it—and recognising that, for example, the Government are focused also on making sure that the right investment environment is there. We see ourselves as a really active part of that, and it is a continued area of very active discussion and focus for our board.

Lord Drayson: Are there some specific actions that you are taking that you could tell us about?

Dr Rich Scott: We reset our mission last year and aligned it to the 10-year health plan. We are looking at all the different ways in which we and the different partners we are engaging with are making sure that we are focused for example in a compliant manner in supporting UK companies. We have a very active programme, and we really value the support of the Office for Life Sciences in thinking about how we are supporting UK SMEs specifically.

I know that is also an area where government is thinking about ensuring that there are the right provisions in place to ensure that that is always compliant. That is something that we are committed to, from the compliance perspective but also recognising the importance of our role to support UK SMEs, for example.

Lord Drayson: We have heard evidence that GEL is difficult to deal with commercially if you are a small biotech. I think the word "impossible" was used. We also have heard evidence that there is a sort of cultural bias within the UK and within the NHS. There is the cliché of "Nobody gets fired for buying IBM", so if you replace the word "IBM" with "Google", it becomes "Nobody gets fired for choosing Google or Amazon". But smaller companies find it very challenging to compete, particularly when these companies have people on the board of the organisations that are controlling these processes.

The Chair: Lord Drayson, I think we probably need to move on. Have you come to the end of your questions for Dr Scott?

Lord Drayson: If Dr Scott could just answer that one, that would be really helpful, Chair.

Dr Rich Scott: Our focus is on making sure that we support UK SMEs, alongside other SMEs; we have a really active programme there. We see it as a really important area of support, as part of the wider government approach.

The Chair: Thank you. We are coming to an end. Dr Scott, you have been marvellous in answering so many of our questions. Just a couple more.

Q43 **Lord Patel:** My question is quite brief. Before that, to follow Lord Drayson, when the NHS uses, for instance, the BRCA test for that mutation, we pay for it. Is it possible that any mutations you identify for any disease through the genomic sequencing could be patented, so that anybody else using it outside the NHS would have to pay for it?

Dr Rich Scott: That is not an approach we take. I have one extra point I just wanted to develop in answer to Lord Drayson's last question. When Genomics England started, the view was that Genomics England holding IP was a really important part of capitalising for UK plc. Lord Drayson's characterising of Genomics England's policy on IP as being a barrier was something that I definitely heard early on. It is an area where we have adapted our approach, to be more supportive of companies that want to come and innovate. That may be an area where your last witness has not engaged more recently. It was perceived as a barrier, but it is an area where we have updated our policy.

We think that, for example, IP on specific genomic variations is not something which actually promotes those sorts of benefits. The UK does not pay IP, for example, for testing on BRCA. Although that is an area where I know there has been some discussion historically, the NHS does not pay for IP for BRCA testing or similar types of testing.

Lord Drayson: So, if GRAIL wants to use your IP for one of its diagnostic tests, it does not have to pay you.

Dr Rich Scott: It does. We modified our approach so that we are receptive to SMEs who want to work with us but might be put off and so that there is the principle of fair return, which is at the centre of what we do. So IP absolutely remains part of it, but making it a perceived barrier is not.

Lord Patel: My final question is a brief one. It relates to the datasets that you hold because of the advantage of genomic medicine and clinical records being linked. From your experience, are there lessons to be learned for the Health Data Research Service, for instance—particularly around the issues related to trust, in that the public have to trust that any data collected on their behalf is being used properly?

Dr Rich Scott: Absolutely. Building and maintaining public trust is a really important area where, right from the beginning of our work, we have seen it as a central part of what we do and of, as I mentioned, the evidence that we generate on the diversity of public opinion. So we have

to be really proactive there; there can be an anxiety in some areas about being on the front foot and engaging. I know that that is, and will be, an area where the Health Data Research Service will want to take a similarly proactive approach.

To be clear, this is in every sense about benefit to individuals through better healthcare, benefit to UK plc and benefit to the growth agenda; they push in the same direction. Part of that is about being really clear on that to the public so that people understand why this is the right approach to take: it is one from which they benefit individually, but there is also that strong buy-in in terms of the national picture. Being upfront about that is important.

Lord Patel: There were recent reports—I do not know whether they were accurate; they were certainly in the media—about codes and datasets for the UK Biobank being published.

Dr Rich Scott: One of the really important bits for us is the model that we use. At Genomics England, the way in which the research library is run—it has been so right from the beginning—is that it works as a reading library, not a lending library. People visit the data; they cannot take the data away. If they export for publication, that goes through a formal process, and access to the data is overseen by an independent access review committee. Building that model and maintaining that reading library approach, which is important, has been at the heart of what we have done.

The Chair: Thank you very much. You will be relieved to hear that the last question is coming up, Dr Scott. You have been excellent in answering so many of our questions.

Q44 **Lord Duncan of Springbank:** This is a question you may not be able to answer, given your relationship with government. Obviously, our report will be about how government can do things better and will focus on recommendations that would help the Government refine their output. Are there areas on which you think we should be focused in our report in order to encourage or discourage the Government, depending on your approach to this issue?

Dr Rich Scott: Partly from a genomics and health data perspective, the fact that we are talking now, nearly a year on from the 10-year health plan and life sciences sector plan, puts us in a really strong position on the biggest thing: clarity from government on the direction of travel and commitment to investment in these areas. That clear signalling is there; we have seen it repeatedly from Governments over the years. That is the single most important thing to maintain.

Aligned to that is continued investment in those areas, as is set out in those plans for the digital infrastructure, which is so crucial to bringing this to life—whether it is thinking about the advances at the more innovative end or about the answer to making this part of everyday

healthcare. That integration piece is right there, empowering individuals. That is really important.

The Government have, again, been really been supportive—I have given the example of the MHRA—in streamlining and taking an innovative approach to standards and regulation. That is another area where we see real progress and promise; continuing that is really important. There is also continued confidence to have that positive engagement on why we are doing this: this is a fantastic area of innovation for individuals, as well as nationally and collectively. Being confident in that approach is important. For example, the creation of the Health Data Research Service is a really positive sign in that direction. It is about thinking innovatively and proactively, and making sure that this is a joined-up approach.

Lord Duncan of Springbank: A previous witnesses mentioned some of the issues around privacy, with doctors and patients being a little reluctant to engage with this. Are patients' discretionary rights in this area something that you would anticipate being a challenge going forward?

Dr Rich Scott: It is really important to establish, first, what the public—the people whose data we are talking about here—want. From the beginning of Genomics England, we have had a participant panel, which is part of our governance, but, as you have heard, we also engage broadly with the public. It is really interesting that, when you talk about these areas, people are clear on the need for their data to be used in certain ways in order to improve their care and improve broader care in future.

Certainly, in that area—I speak now as a doctor and a scientist by background—parts of the medical and scientific community can be paternalistic or maternalistic about their views on what the public might think here. We need to engage proactively in that discussion with the public, as well as with the professions, to be clear on what the benefits are and to give people confidence. A lot of these areas are areas where people do not feel expert themselves and can feel nervous; it is part of that broader engagement bit. This is an area that needs continued focus. It comes from a positive place, in wanting the best, but it can be a barrier when people do not understand how aligned these interests are in both of those different areas: personal benefit and collective benefit.

Lord Duncan of Springbank: That is helpful.

The Chair: Dr Scott, you have conveyed your excitement about the enormous potential for genomics very well indeed—we are very grateful—and you have dealt with our many questions very comprehensively. Thank you very much. This public evidence session is now concluded.